

Virginia I. Jones Alzheimer's Disease and Related Disorder Council

Meeting Minutes from November 20, 2013

Council Co-Chairs Alice Hedt and Brian Hepburn welcomed all members and the Department of Health and Mental Hygiene and the Maryland Department of Aging staff members. The meeting was facilitated by Alice. Each member introduced themselves:

- Cass Naugle, Executive Director of the Greater Maryland Alzheimer's Association
- Karen Lakin, Cedar Creek Associates and Senior Network, Inc.
- Dr. Kimberly Johnston, R.N., Quality Trust for Individuals with Disabilities
- Tonis Paide, consumer of services and person living with Alzheimer's Disease
- Therese m. Goldsmith, Commissioner, Maryland Insurance Administration
- Ilene Rosenthal, Greater Maryland Alzheimer's Association
- David Loreck, Baltimore VAMC, Department of Mental Health
- Richard Neuworth, Lebau & Neuworth, Baltimore
- Banghwa Lee Casado, University of Maryland, School of Social Work
- Bill Neely, Chaplan Brooke Grove Retirement Village
- Victor Henderson, Maryland Department of Disabilities, Secretary's designee
- Ernestine Jones Jolivet, daughter of Ms Virginia I. Jones
- Tim Lawrence, representing Delegate Joseline Pena-Melynk
- Cynthia Fields, Medstar Good Samaritan Hospital
- Karen S. Kauffman, R.N., University of Maryland
- William Mansbach, Mansbach Health Tools, LLC
- Alice Hedt, State Ombudsman, Maryland Department of Aging
- Brian Hepburn, Executive Director, Mental Health Association, Department of Health and Mental Hygiene
- Andres Salazar, Sacred Heart Home; Milford Manor nursing and rehab, Manor Care at Rossville, Morningside House, Greenhouse Residences, Rainbow Adult Day Care
- Michelle Upchurch, Administrator, Potomac Valley Nursing and Wellness Center (on phone)
- Observer: Ms. Karen Paide, caregiver and spouse of Mr. Tonis Paide

Staff:

Erin McMullen, Department of Health and Mental Hygiene
Donna DeLeno Neuworth, Maryland Department of Aging

Donna and Erin reviewed Council logistics to include:

- a membership form of all the members and their contact information will be emailed to the members so you know who is serving on the Council and how to contact a specific member;
- a reminder to please file Ethics Commission forms if not done already and
- a way to keep all the work and documents on file so every member can easily access them is to set up a Google Docs account – Erin will provide some basic training.

Alice reviewed the statute with members and asked each member to read the statute and the 2012 Alzheimer's Commission State Plan if they haven't already.

Alice summarized the main charges of the Council per the statute:

1. Support prevention and early detection of Alzheimer's Disease and Related Disorders, including early stage identification;
2. Address chronic disease factors contributing to disparities in Alzheimer's Disease;
3. Enhance the quality of care;
4. Improve access to and coordination of services and knowledge of the resources for consumers; and
5. Improve data collection capacity.

Ernestine and others who served on the Alzheimer's Commission provided historical context for their work that established this Council. She stated that the Commission reviewed and identified available resources for persons with Alzheimer's Disease and caregivers; they also identified the need to build awareness about the resources so people would have better access to services. The journey with Alzheimer's Disease is difficult enough but the Council can help make the journey easier, Ernestine added.

Cass stressed the importance of getting data collected because we don't know a lot about Alzheimer's Disease in Maryland. Ernestine also stressed we need to gather data and be mindful of the health disparities and data on the African American and other communities. Karen Kauffman said there is no central clearinghouse for the caregiver and consumer. Maryland Access Point (MAP) is a fairly new initiative that the Commission thought incorporating into their recommendations for access to information and services. Andres stated we don't want to reinvent the wheel –there is so much information on the Alzheimer's Association's website, which he encouraged members to review. Members discussed the importance of developing a public education campaign and that this would be a big part of the Council's work.

Cass reviewed the timeline of some studies and commissions in Maryland:

- 1984 was the first established Council and we were excited about the research and dug in to do the work; It was a three year effort with limited state resources;
- Then there was a short-term group – for one year that developed a state plan. Before that there was a group that met for six months and completed a report to the legislature ;
- Now we have this Council.

Discussion followed about the Council's organization and how members wanted to work.

Council's Organization

Erin reviewed the crosswalk and handout she prepared and suggested the different workgroups be formed for most of the work the Council is charged with accomplishing per the statute. The establishment of three workgroups was presented to the council. All workgroups and the full commission would be tasked with continuing the work that was initiated by the Maryland Alzheimer's Disease and Related Disorders Commission, including the development and monitoring of the 2012 Maryland State Plan on Alzheimer's Disease and Related Disorders.

The first workgroup would focus primarily on Goals 1 and 2 of the Alzheimer's State Plan which requires the development of strategies and action related to prevention and detection of Alzheimer's disease, addressing chronic disease factors associated with the disease, enhancing the quality of care, and improving access to and coordination of resources. The second workgroup would focus on Goal 2 (Strategy 4) and Goal 3 (Strategy 1) of the State Plan, which requires the review of state statutes, policies and programs to improve services for those living with Alzheimer's disease with an emphasis on expanding home-and-community-based support and service programs for this population. The third workgroup would be tasked with addressing all of Goal 4, and part of Goal 3 (Strategies 2 and 3) of the State Plan. This requires the development of a public education campaign focused on certain areas identified by the previous Alzheimer's Commission. Finally, the full commission would focus on improving data collection capacity on Alzheimer's disease.

Two perspectives on organizing were discussed; one idea is to determine what the end result of the Council will be and work towards that. Another idea is have each subcommittee determine what steps its group can take to move forward on the 2012 Commission recommendations.

Members expressed concerns about the timeline of getting some of the work done in time for legislative budgetary requests the Council may want to develop; other members expressed concerns and raised questions around when to have the next full Council meeting and did not want to wait until April when the legislative session is over. It was decided that the Council will have one more full Council meeting in January and then at that meeting have more time to do some planning and break up into subcommittees to do some work, then reconvene as a full Council in the spring.

The members also discussed the need for some basic training on Alzheimer's Disease since so many members are knowledgeable about the disease, but have varying levels of understanding. It was suggested to seek out presenters on the disease and also have a knowledgeable person from the National Policy Council of the Alzheimer's Association come speak to the Council on how other states developed and implemented the State Plan. Members agreed this would be instructive for them moving forth with Maryland's State Plan implementation.

Presentation by Ms. Michelle Wojcicki, Maryland Health Benefits Exchange

Michelle gave an overview of the Affordable Care Act (ACA) provisions and the Maryland Health Connection. Members discussed the provisions as it would relate to older adults, people with Alzheimer's Disease and related dementias and caregivers.

Members expressed concerns regarding how an older adult can understand and then navigate such a complex system.

The next meeting of the full Council will be held on Monday, January 6, 2014 at the same location as the November meeting at the Spring Grove Hospital Campus, 55 Wade Avenue, Dix Building, Basement Conference Room, Catonsville, MD

Each member was asked to consider what workgroup they are interested in serving on, keeping in mind that people outside of the Council members could participate in a workgroup.

The meeting was adjourned at 4 p.m.

